



TIP SHEET

Engaging with Schools to Support Your Child with Psychosis

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Having a child with mental health concerns, especially the complex and confusing issues related to psychosis, can be stressful and worrisome for families. It's important to remember that recovery from psychosis is not only possible, but *expected* with effective interventions. Maintaining a positive and encouraging attitude, and keeping in mind this hope, is a crucial part of recovery.

Increasing your own knowledge of the signs and symptoms of psychosis will allow you to become a stronger advocate for your child. Partnering effectively with schools and other professionals can help facilitate early detection and a quicker, more successful recovery. In this document, we present information and resources to (1) help families recognize early signs and symptoms of psychosis and (2) work together with schools and community mental health professionals to help your child thrive and succeed despite the challenges of psychosis.

BACKGROUND

Approximately 3 in 100 people experience psychosis in their lifetime, with signs and symptoms often emerging in adolescence and young adulthood, sometimes as early as high school or middle school. Without effective intervention, psychosis can disrupt school performance, peer and family relationships, social functioning, and goal setting. A substantial research base suggests that specific approaches to treatment provided early in the experience of psychosis are most likely to achieve the best outcomes. ***These approaches focus on keeping students engaged in school and other activities, and they are effective in helping students experiencing psychosis stay on their life courses.***

The most prominent symptoms of psychosis are delusions, which are ideas or beliefs held tightly despite contradictory evidence, and hallucinations, which involve perception in the absence of stimulation (for example, hearing voices that others cannot). Other symptoms of psychosis can include problems with attention and memory, disorientation, extremely disorganized thinking, and depersonalization. However, psychotic disorders typically begin with milder symptoms, such as unusual thinking, withdrawal from others, or unusual actions such as peculiar hygiene or social isolation.

Psychosis often causes young people to withdraw and become mistrustful, and therefore less likely to share their symptoms or distress. They might also fear consequences of sharing their experience because of the stigma prevalent in society and the media. As a result, it may not be immediately obvious to family members that someone is struggling with psychosis.

Psychosis exists on a spectrum and, although the most prominent disorder with psychosis is schizophrenia, psychosis can occur in a variety of disorders such as depression, bipolar disorder, autism, and substance use. The exact causes of psychotic disorders are unknown, but it appears to result from a combination of genetic and environmental factors. Psychosis transcends all societal and cultural boundaries, so anyone can develop psychosis.

SIGNS OF PSYCHOSIS

The long-term outcomes for people with psychosis are variable, yet research suggests that ***recovery should be the expectation***. An essential factor in supporting recovery is early identification and reducing the length of time between the onset of symptoms and treatment. When adolescents are identified as having early signs for psychosis, plans can be implemented to monitor developing symptoms and intervene early if they continue to progress.

There are no blood, genetic, brain scan, or other biological tests that can accurately diagnose psychosis. Rather, a diagnosis depends on identifying symptoms and behaviors.

HERE ARE SOME INDICATIONS THAT A STUDENT MIGHT BE EXPERIENCING PSYCHOSIS:

- Seeing, hearing, feeling, smelling, or tasting things that others cannot
- Being distracted by mild or nonexistent stimuli (e.g., being more sensitive to lights or sounds)
- Being overly mistrustful (e.g., constantly guarded, believing others are speaking about them behind their back when that does not appear the case to others)
- Preoccupation with unusual ideas
- Often saying things that do not make sense (e.g., using incorrect words, excessive rambling, going on tangents, or being hard to follow in a conversation)
- Believing they are exceptionally better than others without any evidence
- Feelings of derealization or that there is something “off” with others or the world
- Feeling as if they are not in control of their own thoughts
- Decrease in self-care or hygiene
- Showing inappropriate emotion (e.g., laughing at sad things)
- A significant drop in grades
- Extreme fear
- Clear changes in sleep or eating
- Spending more time in their room, altering their room

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- Spending less time with friends, reporting friends have mistreated them (without evidence), or that others have told them to stay away from them
- Spending less time doing hobbies or sports they previously enjoyed
- Trouble thinking clearly and/or concentrating in class
- Decrease in or lack of motivation
- Decreased activity level
- Showing less emotion, or showing little expression or reaction to good or bad events

Some of these behaviors may be typical in young people. For example, high-school students can be gossipy, so it might be appropriate to be suspicious in some social situations. But if your child is consistently experiencing difficulties with others, or has multiple of the signs above, it might be helpful for them to see a clinician to distinguish whether it is healthy adolescent behavior, potentially depressive or anxiety symptoms, or something such as psychosis. Early detection and intervention is strongly related to positive outcomes for youth experiencing psychosis.

EFFECTIVE TREATMENT AND INTERVENTIONS

THERE ARE MANY TYPES OF TREATMENT AVAILABLE FOR PSYCHOSIS, INCLUDING THERAPY AND MEDICATION.

The research is particularly strong around Coordinated Specialty Care (CSC), a collaborative, recovery-oriented, multifaceted treatment approach focused on promoting individualized and integrated interventions based on a person's own life goals. A core component of CSC is Supported Employment and Supported Education, services provided by a dedicated member of the treatment team to facilitate the student's work and school success. There are more than 250 CSC programs available across the country. If CSC services are not available near you, consider advocating for the different unique elements within this model (e.g., supported education, goal-setting) that might be effective in supporting your child.

SAFETY PLAN

Young people are at increased risk for suicidal thinking, drug/alcohol abuse, and other dangerous behaviors. If your child has a mental health concern, especially if it includes psychosis, it is important to have a safety plan in the case of an emergency. Although it may be difficult to think about, developing a safety plan is a proactive, helpful precaution to prevent a crisis. Some good practices during this time include inquiring sensitively but directly about

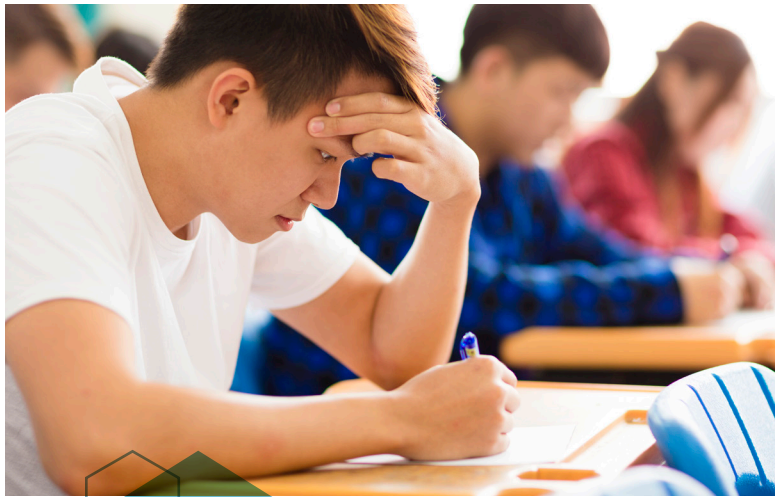
suicidal thoughts, eliminating access to firearms, and identifying crisis intervention services like local 24-hour crisis hotlines and other “warm-lines” that offer an alternative to contacting police or emergency medical services amidst a conflict, misunderstanding, or threat.

Safety plans can be developed in partnership with providers and schools and should address issues that may arise in a school setting. Identifying triggers at school, recognizing signs of escalation, ensuring that trusted adults (including school staff) are sensitive to the situation, allowing for the student to have breaks if needed, and identifying safe spaces (at home, at school, and with peers) when your child is feeling overwhelmed all can improve safety and reduce negative interactions

with others. In addition, it is always a good idea to ensure that the school has your current contact information and phone numbers for mental health providers who might help during an urgent situation.

SELF-CARE FOR FAMILIES

Psychosis affects the individual, but also can be difficult for parents, siblings, and extended family to understand and manage (just like other complex medical conditions in a child). You may want to explore local support groups and seek therapeutic help to address practical issues, manage your own emotional reactions, and learn how best to support your child. The *Resources* section at the end of this document provides information and details about various support networks for parents and family members of someone with psychosis. Throughout your experience, using available resources will help you maintain an active voice in your child’s recovery.



COORDINATING WITH SCHOOLS

DISCLOSING A DIAGNOSIS

Parents often struggle with whether they should share that their child is experiencing symptoms of a mental illness, including psychosis. The important benefit of sharing this information is that the school and teachers can partner with you and your child to make informed and appropriate accommodations. Sharing information will facilitate better communication over time with the school about how your child is functioning academically and with peers. It will also give teachers context in case your child is frequently absent or behaves unusually in the classroom. When schools are not aware of extenuating circumstances or conditions, they may be left to speculate on causes of the student's changes and sometimes resort to disciplinary responses intended for students who are deliberately acting out. Although disclosure creates a possibility that your child will feel stigmatized or labeled, partnering with the school usually allows for more effective collaboration to support your child's school success and recovery.

REDUCING BULLYING

Students with psychosis are at risk for teasing, bullying, social withdrawal, and other social concerns. Discuss any signs or concerns of bullying with school staff, while being mindful that it is possible that your child is misinterpreting the actions or words of others. Collaborating with school teachers and administrators about how to manage these situations can diminish bullying and stigma. Specifically, alerting schools to comments from your child about others may help the staff recognize subtle or "sneaky" bullying or mistreatment by others.

Most important, collaborating with schools allows all adults involved in supporting your child to respond in consistent ways and to identify, as a team, what approaches work best in various situations and with different peers. For example, it may quickly emerge that going to lunch in the cafeteria is overwhelming to the child, but going to lunch five minutes earlier with some close peers in a preferred location diminishes social difficulties. You might also want to request that the school provide all students with basic information, appropriate to their age, about psychosis and the unique challenges it poses, emphasizing that students with psychosis are similar to everyone else. Skilled facilitators (often mental health providers or school clinicians) can help make sure the message is received correctly. A peer mentor equipped with additional knowledge about mental health concerns can provide a buffer between a student with psychosis and other students.

SETTING GOALS

Like every other student, your child has goals and aspirations. By attending to these goals through collaborative planning, career counseling, guidance with college, and other supports offered to all students, schools can keep a child who may be struggling on the right track. In partnership with school staff, you can support your child to recognize that the path to achieve their goals may be a bit different, but the goals are still very much achievable and worth pursuing.

ENGAGING SUPPORT AND ACCOMMODATIONS

Federal laws guarantee students experiencing a mental illness or psychiatric disability access to a free, appropriate education that supports their individual needs and learning styles, just like students with other disabling conditions. Your school can provide specific support and accommodations reflecting your child's individual learning style, strengths, and difficulties.

The Individuals with Disabilities Education Act (IDEA) is a federal law ensuring that students with any disabilities, including those caused by psychiatric illnesses, receive free and appropriate public education services specific to their individual needs in order to provide them with the same opportunities as students without disabilities. Under IDEA, the educational requirements (e.g., for graduation) may be changed and the student can receive “modifications”

to make effective progress given the disability. An **Individual Educational Program (IEP)** often is implemented for students experiencing psychosis whose symptoms, such as delusions or paranoia, either interfere with or are worsened by regular classroom situations. For more information, visit <https://sites.ed.gov/idea/regs/c/e>

To be eligible for an IEP under IDEA, a student must have a disabling condition (diagnoses are helpful but not essential for this), the disability must be interfering with the student's educational progress (e.g., academically or socially), and the disability must require specialized instruction, beyond what a typical teacher would be expected to provide. Eligibility for an IEP is determined by the child's parents/guardians and a team of

qualified professionals including the student's teacher and at least one clinician qualified to administer diagnostic evaluations (e.g. school psychologist, speech-language pathologist).

A parent or guardian can ask the school district to pay for an independent educational evaluation by an outside expert. The school district is not required by law to agree or provide this, but sometimes an independent evaluation is done when the student's clinicians and the school clinicians disagree on the student's disability or needs. Once eligibility is established, the student's parents and an official IEP team are tasked with establishing a comprehensive program to meet the student's specific needs.

Section 504 of the Rehabilitation Act requires schools to provide appropriate supportive services for students with disabilities who do not require an IEP. These plans are designed to help children with any type of disability, including attention and learning issues that limit one or more aspect of basic life, such as learning. With a **504 Plan**, the student may receive accommodations to meet regular academic requirements. These plans are established to protect students with disabilities from discrimination and give them access to the rights of all students. Helpful 504 Plans involve a thoughtful transition plan that considers the student's future goals



and suggests ways to help the student make a successful transition to adulthood. For students with mild or occasional psychosis symptoms, a 504 Plan is often sufficient to support their effective progress.

Even before the initiation of a 504 Plan or an IEP, a school may offer a “Response To Intervention” (RTI) plan, which allows the school to immediately provide effective supports for the student’s needs. For students with psychosis, an RTI plan may be implemented to immediately address circumstances at school that may be contributing to worsening symptoms. Often students displaying initial signs of psychosis symptoms may receive an RTI plan while the student’s mental health status is more thoroughly evaluated, sometimes by the school, and sometimes through outside mental health providers or at a psychiatric hospital. Sometimes medical conditions, such as hyperthyroidism, medication interactions, or substance use cause psychosis symptoms, and treatment of these underlying conditions eliminates the psychosis symptoms and need for an educational plan.



If your child requires hospitalization, you will want to work closely with your child’s school to ensure a smooth transition back to school after discharge. Ideally, you will begin working collaboratively on a transition plan as soon as you notify the school of the reason for your child’s absence. The transition plan might include accommodations such as providing your child with class notes or extending his or her assignment deadlines, identifying any emotional triggers or stressors, or providing a “safe place” for your child to go during the school day if needed.

Sometimes, a student may gradually return to classes and spend part of the day with therapeutic staff. Monitoring the success of the plan, and your child’s readjustment to the school routine, will help support your child’s transition back into the school building and each class.

SEEKING AN IEP, 504, RTI, OR TRANSITION PLAN

To start the process of requesting accommodations, ask your child’s principal to identify and contact your school district’s IEP and/or 504 coordinator. The coordinator likely will ask you to make a request in writing and provide documentation of your child’s disability. Schools are expected to identify appropriate services and respond to your request within a specific interval of time, usually 30-60 days. The school will then initiate a team meeting to conclude which accommodations might help your child.

When a child does not qualify for an IEP, a 504 Plan may be a good option. Schools may not automatically include you when developing the plan, so let them know if you want to attend student planning meetings and be updated about the process when you make the initial request. You have the right to know when the school district is meeting, which accommodations they approve, and any evaluations they conduct, as well as the right to challenge the decisions they make.



COMMON EDUCATIONAL INTERVENTIONS FOR PSYCHOSIS ARE BASED ON INDIVIDUAL NEEDS AND MAY INCLUDE:

- **School-based counseling:** Counselors work with students to address psychosis symptoms, review school-related stressors, work collaboratively on goals, and help with social well-being (e.g., social skills, reducing bullying). School-based counseling is usually provided to help the student access the school curriculum and engage meaningfully with peers at school, and is not a replacement for external specialized mental health treatment.
- **Medication accommodations:** School nurses can help students administer medication at school, and teachers can allow students to leave class to receive medication or address side-effects (e.g., thirst, hunger, fatigue, jitteriness).
- **Alternative environments in the school to decrease psychosis symptoms:** Quiet spaces to complete work or exams can be identified, both inside and outside (e.g., library or counselor's office) the classroom.
- **Alternative content and assignments:** If students are distressed by certain aspects of their lessons or curriculum, offering an alternative curriculum that will not trigger or worsen the distress may be appropriate.
- **Preferential seating:** Having the option of sitting away from distracting peers or noisy areas may help some student with intruding noises that may increase stress, psychosis symptoms, and inattention.
- **Extra time to complete exams:** Students with psychosis may be distracted by delusions or hallucinations, as well as the sedating effects of antipsychotic medications, so extra time can be appropriate.
- **Flexible deadlines on assignments:** Symptoms can ebb and flow, so extra time may need to be provided, particularly for complex or long-term projects.
- **Note-taking assistance:** Teachers or aides can provide class notes or record classes to help students stay focused on the relevant information, since psychosis symptoms may interfere with attention to the material presented by the teacher.
- **Alternatives for public speaking assignments:** Speaking in front of peers can exacerbate symptoms for some students with psychosis, so teachers can allow presentations in alternate formats (e.g., recorded or just for the teacher) that would be less stressful.
- **One-on-one educational aide:** Aides can shadow students to help them reach their academic goals and serve as a calming and trusted adult presence.
- **Extra assistance in organization:** School staff can help students organize homework, review assignment logs, and provide home-school communication sheets.
- **Help applying and enrolling in post-secondary school:** Counselors should help students reach their college goals (e.g. financial aid assistance, application guidance, etc.), regardless of disability.

Available accommodations are not limited to the list above and should be customized to address the individual's unique needs. For example, a student with psychosis might have difficulty staying awake or paying attention in class because of the sedating effects of antipsychotics. A school could support that student by offering note-taking assistance, breaks to lie down, or extra time for completing exams. Establishing an ongoing collaborative, partnered relationship with your school best positions you to refine and adapt school-based interventions to support your child. Creatively crafting a plan unique to your child is often what is required for the best outcomes.

PREPARING FOR SCHOOL SUPPORT TEAM MEETINGS

Whether part of a formal educational plan or not, you are entitled to meet with your child's teachers to discuss any educational concerns. Consider preparing for these meetings with any explicit concerns you have (e.g. test scores, grades, behavior) as well as any information

about your child that the teacher might benefit from knowing (e.g. strengths, emotions, areas of concern, triggers, social network). Highlighting your child's strengths and goals can set a positive tone for the conversation. You can collaborate with teachers to set goals for your child and discuss ways that school and home life can support him or her. Teachers may also be able to help you understand concerns about your child's behavior in the context of what is typical for their age range.

Although supports for students with psychosis are mandated by law, there is wide variability in terms of how plans are crafted and implemented. In some cases, there might be differences between your expectations and what the school is offering.

Collaboration, trust, and patience improve the school-parent collaboration and commitment to any efforts at school. Accountability, timelines, documenting communication, and having clear expectations also increase successful outcomes.

If this process is unfamiliar or feels stressful, consider bringing others, such as friends, family members, or trusted other educators, with you to school meetings. In addition, you may seek counsel and support for this educational process through a Parent Support Provider, a certified individual who may be more familiar with legal requirements of schools and advocating for the appropriate services. You can also confer with educational attorneys in your area for additional support or clarity regarding options for your child.



HELPFUL RESOURCES

TO EDUCATE

More Information about Early Psychosis

Recovery After an Initial Schizophrenia Episode (RAISE)

A National Institute of Mental Health (NIMH) funded research initiative focused on improving methods of early identification and intervention of psychosis. The RAISE website provides detailed information on psychosis, recovery-oriented treatment programs and other relevant resources for patients and families affected by psychosis:

<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml>

Prodrome and Early Psychosis Program Network (PEPPNET)

A national, interactive network of experts that shares current and comprehensive information about early psychosis and promotes access to appropriate treatment options:

<https://med.stanford.edu/peppnet/earlypsychosis.html>

uthink

An educational resource that guides school staff and young people, through the experience of mental illness and how to deal with related issues:

https://marylandeip.com/_static/meip/uploads/files//uthinkresourceforschools.pdf

An Inventory & Environmental Scan of Evidence-Based Practices for Treating Persons in Early Stages of Serious Mental Disorders

An informational tool focused on meeting the needs of those suffering from serious psychiatric illnesses, that includes detailed examples of various coordinated specialty care models which guide consumers in implementing evidence based practices:

<https://www.nasmhpd.org/sites/default/files/Environmental%20Scan%20%202.10.2015.pdf>

NIMH State Health Administrators and Clinics

A range of treatment and educational materials compiled by the National Institute of Mental Health:

<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/state-health-administrators-and-clinics.shtml>

Maryland Early Intervention Program

A state of Maryland specialized treatment team with an informative website:

<https://marylandeip.com/eip-resources#!Voices-of-Recovery>

<https://marylandeip.com/>

<http://mdbehavioralhealth.com/training>

On Track NY

An innovative treatment program for adolescents and young adults in New York with an informative website

<http://www.ontrackny.org/>

National Alliance on Mental Illness (NAMI)

A national platform for individuals, families and caregivers to find information on everything from local support groups, advocacy, psychoeducation and other mental health resources:

<https://www.nami.org/About-NAMI>

Understood

A non-profit consortium of organizations concerned about children with learning and attention issues that offers excellent resources regarding developing an IEP or 504 Plan:

<https://www.understood.org/en>

Voices of Recovery

The Center for Practice Innovations at Columbia Psychiatry New York State Psychiatric Institute provides an inspirational collection of personal accounts of overcoming psychiatric challenges, including psychosis:

<https://vimeopro.com/user23094934/consumer-and-family-portal>

TO REFER

Finding Appropriate Treatment Options

Snapshot of State Plans for Using the Community Mental Health Block Grant Ten Percent Set-Aside to Address First Episode Psychosis

A SAMHSA-funded technical assistance resource providing contact and other information for more than 250 first episode psychosis programs across the country, updated annually through 2018:

www.nasmhpd.org

Program Directory of Early Psychosis Intervention Programs

A comprehensive list of mental health resources across the U.S. that specialize in early intervention programs for psychosis:

http://www.easacommunity.org/PDF/Directory_V5.pdf

SAMHSA Behavioral Treatment Locator

A confidential, online tool that can be used to locate specialized treatment facilities in the US for both mental health and drug abuse problems:

<https://findtreatment.samhsa.gov/>

NAVIGATE

An initiative supported by the NIMH to identify and treat first episodes of psychosis. With 20 treatment sites throughout the US, NAVIGATE implements a specialized treatment program for early psychosis to a diverse and widespread population:

<http://navigateconsultants.org/>

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